

STATE OF HAWAII DEPARTMENT OF HEALTH

P. O. BOX 3378 HONOLULU, HI 96801-3378 In reply, please refer to:

STATE TRAUMATIC BRAIN INJURY ADVISORY BOARD (STBIAB) MEETING MINUTES of January 22, 2015

Present: Albert Burian, Rita Manriquez, Lila Ota, Bill Rodrigues, Mary Wilson,

Stephanie Yee, Kawena Young

Excused: Robert Sloan, M.D.

Others: Evelyn Bautista, Hawaii Neurotrauma Registry (HNTR); Lyna Burian, Brain

Injury Association-Hawaii (BIA-HI); Kevin Furutani, HNTR; Violet Horvath,

PhD. Director Pacific Basin Rehabilitation Research and Training Center

(PBRRTC)/HNTR

DOH Staff: Curtis Inouye

- I. Call to Order Acting Chair William Rodrigues called the meeting to order at 1:45 p.m. Quorum present.
- II. Approval of Minutes –Board Member Rita Manriquez mentioned that under Section V. Old Business (D): Neighbor Island Activities of the November 20, 2014 STBIAB Meeting Minutes: correction to Minutes is noted below in Section V. Old Business (C). Board Member Kawena Young motioned to accept the Board minutes of November 20, 2014 with correction as mentioned above. Board Member Mary Wilson second the motion. Board members voted to accept the Minutes with corrections.
- III. Review of Agenda Chair Rodrigues reviewed the Board's agenda. Board Members accepted agenda with no changes.

IV. New Business

A. Traumatic Brain Injury Binder:

Copies of the revised TBI Binder inserts were provided to Board Members for their review. Board Members to review the TBI inserts and provide feedback at the next STBIAB meeting in March, 2015.

V. Old Business

A. Concussion Management Project Update: Defer to next STBIAB meeting on March 20, 2015. B. Pacific Basin Rehabilitation Research and Training Center Hawaii Neurotrauma Registry (HNTR) Update:

Violet Horvath provided an update on the HNTR Project up to December 31, 2014. She reported that there are 85 unique participants in the registry. There are a few more women than men in the registry. Most of the participants reside on Oahu but there are 7 from Hawaii Island and one each from Kaua'i and Maui. Most list TBI as their major injury followed by stroke and 12 participants indicating having a spinal cord injury. HNTR had one public event this period where 36 individuals visited their table. HNTR materials, brochures and information on the registry were provided. One print ad and one radio PSA was completed during this period. The HNTR Advisory Board is scheduled to meet in early 2015. Currently, there are five board members from Oahu and Violet is looking to have Neighbor island participants on the Advisory board. HNTR is working on scheduling a presentation by Dr. Anegawa who is a specialist in neurology with the Veterans Administration Polytrauma Team. Violet will inform Board Members when this meeting is scheduled. Violet mentioned that HNTR has made significant progress on their media campaign. Two articles on the HNTR were in the Generations Magazine and a third will be forthcoming. Violet will also be on the Perry and Price show on January 24, 2015. On January 29, 2015, HNTR will be taping two, half hour shows on Olelo. Both shows will be on Neurotrauma with one show focusing on TBI and the other on stroke. Dr. Robert Sloan and Dr. Matt Koenig will be the presenters respectively. There will be survivors of neurotrauma injuries on the show as well. Violet will inform Board Members of the air dates of the shows. HNTR also has a contract with Clear Channel to air the HNTR ads over the many radio stations affiliated with Clear Channel.

HNTR is also researching with other states on the best practices of the national and state neurotrauma registries and Violet mentioned that currently they have results from 12 states. Violet mentioned that these states with registries collect information from death records, hospitals records, EMS records. HNTR seems to be the only project who is looking at participants post discharge. Violet mentioned that their proposal to present on the registry best practices was accepted for the 2015 Williamsburg TBI Conference in mid-April. Currently, the link to the HNTR survey is very difficult to remember so HNTR went out and bought a domain name which is much easier to remember and as soon as it is set up. Violet will provide that information to the Board Members. HNTR also did a presentation in January, 2015 to the Pacific Head Injury Support Group in Kona, Hawaii. HNTR staff were able to provide the registry survey to interested individuals and HNTR staff will follow-up with those individuals who are interested in completing the survey. STBIAB Member Mary Wilson from the Brain Injury Resource Center informed Violet that she is more than willing to set some time aside during the Resource Center's program to have HNTR staff present their information. HNTR staff will assist individuals attending the Resource Center in completing the HNTR survey. Board Member Kawena Young mentioned that aside from being on the registry,

TBI survivors need specific services that will address their specific needs because brain injuries affect different individuals in different ways. As mentioned in the meeting, resources are scarce. However, at these meetings, it is a good time for

Board Members to share about any resources in the community that may assist individuals with TBI in accessing services.

Please refer to the HNTR report which is attached for further information.

C. Neighbor Island TBI Activities:

Board Member Rita Manriquez from Kauai requested changes to the Minutes of the November 20, 2014 STBIAB meeting as mentioned in Section II: Approval of Minutes. Rita mentioned that she received a call from a co-worker of Roxanne Bolden, Aloha Independent Living Hawaii's Executive Director informing her that they will be on Kauai from December 21, 2014 to December 23, 2014. Rita was informed that her interview for the Kauai Independent Living Specialist position will be done during that time. Rita's interview was done on December 22, 2014 and was told at that time that she will be hired as Kauai's Independent Living Specialist. Aloha independent Living Hawaii is on all major islands and are able to assist and provide information on community resources to help individuals with their independent living needs. Rita mentioned that there is no Aloha Independent Living Hawaii office currently on Kauai so she will be working from her home and any intake will be done in a mutually agreed upon location on Kauai. Rita's official start date in that position is January 5, 2015. Rita provided contact information for anyone interested in learning more of Aloha Independent Living Hawaii: Phone: 800-385-2454 or on Facebook at: http://www.Facebook.comAlohaILHawaii

D. DOH Update:

Neurotrauma Special Fund Update:

Current cash balance after contract encumbrance, purchase order claims and other charges, the special fund balance is at 621,639.00.

V. Announcements:

- 1. Lyna Burian from the Brain Injury Association of Hawaii wanted to announce again that she will be asking the legislators to introduce a Bill to require health insurers to cover cognitive rehabilitation. Lyna mentioned that in the 2014 legislative session, the last committee to hear the bill in the House did not pass the Bill due to a lack of a definition for Cognitive Rehabilitation. Lyna mentioned that they will ask legislators to re-introduce the bill with the definition during this legislative session. Individuals interested in supporting the bill or for more information can contact Lyna Burian.
- 2. Board Members discussed the importance of having a "get together" where TBI survivors and others can network and "talk story". It was mentioned that being able to talk about their injury helps them relieve the pressures they go through. Board Members also mentioned that exercise such as Tai Chi and walking helps relieve tension and stress as well. Anyone interested in coordinating this activity can contact Curtis Inouye for support.

- 3. Board Member Kawena Young mentioned that her friend's daughter had lost the ability to speak in sentences. She had been prescribed medication but symptoms continued for nearly two years. She is unable to get help due to her daughter's husband being unable to find a brain specialist willing to work with her. She continues with these symptoms and doesn't seem to be improving. Kawena mentioned that she too had experienced these symptoms after taking a prescribed medication. After discontinuing the medication and doing her own research and therapy, she now is able to speak in sentences. Per Kawena, it is important for individuals with a brain injury or other conditions to look at options in addressing their concerns and medical needs. If anyone has any ideas or recommendations on how she can help her friend help his daughter, please contact her.
- 4. Kawena also announced that there is a new parking rule for individuals with a disability while in metered stalls. DOH staff to report on current metered parking privileges for vehicles displaying special license plates or a windshield placard.

VII. Next Meeting

Date: March 20, 2015 Time: 1:30 – 4:00 pm

Location: Kalanimoku VCC and Neighbor Island VCC sites

Recorded by Curtis Inouye